

Chapter 14

Discussion Points

- Are there any risks associated with children's participation?
- What are the barriers to children's participation?
- What do you understand by the term 'participation' in your area of work?
- How could you involve children and young people in your work?
- To what extent can we involve all children in a participatory way? Or can we?
- How can we develop systems for the effective monitoring of children's participation?
- How can we know when participation has been achieved? Or can we?
- Consider the idea that non-participation is just as valuable as participation.

Introduction

Case Studies

Children play and active role in decision-making

Children undertaking *You're Welcome* (DoH, 2011) reviews recommended changes to a sexual health clinic. Though they were very positive about the staff and the service, they thought that the reception area was very clinical and could be seen from the road meaning that there was the potential for a lack of privacy and confidentiality. The clinical commissioning group responded by setting aside funds to redesign the reception area and asked the children to help with the design (Blades et al., 2013).

Children influence the design of toilets in their school

Pupils on the school council in a primary school in Wales raised the need for improvements to be made to their toilets. As a result, the Head teacher and Friends of the School raised funds to pay for the improvements. The pupils helped staff to plan the work and as a result the toilets were transformed into bright, modern and colorful suites. Mirrors were provided as well as soap dispensers and sanitary provision. Pupils now monitor the areas and report any problems immediately. This work has prompted the teachers to improve their toilets (Clarke, 2004).

PULSE is a group of young people (aged 12-22 years) who believe that "*children and young people's views about health and wellbeing are important and should be gathered, listened to and acted upon*" (PULSE, 2013:2). In both the case studies above, that is precisely what happened. Not only were the children and young people ¹asked for their opinions and views

¹ By 'children and young people' we mean all those from birth to 18 years of age. We also use the terms 'children' and 'young people' interchangeably.

but also they were very clear as to the outcomes of their participation. Since the beginning of the 1990s there has been a drive towards involving children and young people in the development and delivery of services. At no other time in our history has there been so much focus on enabling children and young people to participate in the lives of their communities and the evidence points to a growing recognition of their specific value within society (DoE, 2010; Ahmed et al., 2011; Blades et al., 2013).

What constitutes 'participation' by children is interpreted in many different ways. Often the degree to which they are encouraged or enabled to participate depends largely on the attitude of adults around them and the interpretation those adults place on the term 'participation'. As a result, the current focus of the UK government and other bodies on children's participation can run the risk of being implemented in a meaningless way or not implemented at all. In a period of significant reform, however, there is real opportunity for those who work with children and young people to make children's participation in public health decision-making a reality. This chapter begins by examining the case for children's participation in public health service design and delivery and describing the policy drivers that underpin the situation as it is at the beginning of 2014. The content is then placed firmly in the context of public health, moving on to take a positive approach to enabling participation, presenting ideas for making participation a reality. Then, before concluding, we present a number of case studies to demonstrate examples of good practice.

The case for including the child in service design and delivery

The Department for Education (2010), in its *Policy paper: Positive for Youth* suggests that embedded in national policy is an assertion that children have a paramount role to play in service provision. One reason for involving children in service delivery is the potential for services to improve because of their involvement. Involving children in all levels of service planning, delivery and evaluation can lead to services that are more appropriately equipped to meet their specific needs. As Hart and Chesson (1998: 1602) argue, "*unless children's perceptions . . . are known, services cannot respond to their needs and improvements to achieve high quality care cannot be instigated*".

Research studies have shown that the involvement of children and young people can lead to better decision-making, which is more likely to be based on accurate information and

therefore more likely to be implemented and subsequently to have beneficial outcomes (Thoburn, 1992; Hodgson, 1996). Coyne and Gallagher (2011) in their Irish research exploring the experiences of participation in decision-making by children in hospital, report that all of the children in their study (aged 7-18, n=55) spoke of the need to have information made available to them about their treatment and hospital stay. Some children had a positive experience of being involved in these discussions while others did not. Those children who were actively involved in the decision-making process reported feeling “...valued, happy and less anxious.” (p.2337). In contrast, children who felt less involved reported feelings of confusion, anger, sadness, rejection and betrayal (Coyne and Gallagher, 2011).

Aubrey and Dahl (2006) propose that children’s perspectives on the services they receive can contribute to the development of new knowledge and to the development of more democratic communities. The children (aged 5-11, n=21) in their study, which analysed the views of vulnerable children about the significance of the services they received, found that the children held many valid views that related to their relationships with service providers. In addition, Aubrey and Dahl found that the children would have welcomed more involvement in decisions about services that affected them. Importantly, children themselves have indicated that they want to be involved and, more importantly, that they want to be listened to. Primarily they want to be part of decisions about matters that concern them closely, including the education system, public transport, health, education and advice (Borland et al., 2001). Compilation of evidence from a number of consultation documents with children found that with respect to health promotion, children have stated they want to be involved in the design, development and evaluation of both child friendly campaigns and services (LaValle et al., 2012).

Children give a variety of reasons for why they believe they should participate in decision-making about services, including the fact that it offers them new skills, builds their self-esteem and leads to better outcomes, and because they think children have different perceptions from adults (Lansdown, 2001; Kirby et al., 2003). Coyne and Gallagher (2011) suggest that the factors promoting participation in hospitals are familiarity with the hospital and staff, the age of the child and professional time. Moreover how parents include their children in decision-making has an impact on how the children participate. Coyne and Gallagher (2011) conclude that in some cases health professionals and parents underestimate a child’s ability to participate in decision-making and do not allow the child adequate time to process the

information they have been provided with before they can make a decision. Coyne and Gallagher (2011) call for the development of hospital policies to include the importance of giving children adequate space to make decisions and not to discriminate against children's capabilities based on their age. These authors note that when adults communicate with children in a child-friendly way in accordance with the preferences of the child, it demonstrates to children that adults respect them and take their viewpoints seriously. Indeed Hinton (2008) argues that continuous adult-child communication encourages adults to understand the child's socio-cultural background where language capacity and children's ability are not being confused. Furthermore as the participation of children:

"...improves the quality of care provided, it is an important investment and one that requires adults to move to a child-centred approach in how they relate to children." (Coyne and Gallagher, 2011:2341).

Social and political arguments for involving children in service delivery rest on the fact that they share the same world as adults, coping with similar factors that affect their lives. As Willow (1997) points out, in her review of local authorities, that failing to involve children or consult with them also fails to take into account their specific views and experiences. It fails to recognize children as future citizens and ignores their 'presentness' thereby leaving them without a voice. With no voice, it could be argued that they have no responsibility to contribute to society's norms and rules, which can be 'seen as a form of social exclusion' (Johnson and Ivan-Smith (1998:7).

A society that does not value the contribution of all its members, breeds inequality and divisiveness (Willow, 1997). Promoting children's participation increases their visibility, brings their needs to the attention of adults and can lead to better decision making. In a report on effective government structures for children, Hodgkin and Newell (1996: 38) argue that if children and young people are given more opportunities to participate in the running of society, *"they will be more willing to engage in the processes of democracy"*.

Policy Drivers

"Children and young people are key stakeholders of the NHS and their interests must be at the centre of health and local government services."

(Royal College of Paediatrics and Child Health (RCPCH), 2011: 2)

Since the first edition of this book was published in 2007 the UK government has undergone major change. In 2010 the UK came under the leadership of a Coalition Government, the first peacetime Coalition since the 1930s (Brooks, 2013). Prior to 2010 New Labour had laid the foundations for the new Coalition's formulation of policies around children that recognised the importance of acknowledging their participation rights (Brooks, 2012; Davies, 2013).

At the end of 1991 the British Government signed up to the United Nations Convention on the Rights of the Child (UNCRC) (1989). This international treaty gives children a voice, and at the same time presupposes a more socially active role for them. By acknowledging that children still need protection and provision by adults, as well as the right to participate in decisions affecting their lives, the UNCRC recognizes the role of children as social actors. In 2014 the UK Government will report to the committee on the rights of the child on how they have implemented the UNCRC (CRAE, 2013). The draft report, published for consultation in October 2013, describes the policy changes affecting children yet no analysis of how these changes have impacted on the lives of children themselves is evident (CRAE, 2013).

In 2003 the commitment to improving the lives of children, young people and their families was strengthened by the publication of the Green Paper *'Every Child Matters'* (Chief Secretary to the Treasury, 2003), which proposed changes in policy and legislation in England to intensify the focus of services around the needs of children, young people and their families. Support for the proposals was clearly evident in its intention to base services on outcomes identified by children themselves rather than via prescribed organizational change alone. At the beginning of March 2004, the Children Bill was published alongside *'Every Child Matters: the next steps'* (DfES, 2004) and the Bill received Royal Assent in November 2004. The Children Act (2004) provides the legal framework for the programme of reform outlined in the Green Paper (Chief Secretary to the Treasury, 2003). The Act was an attempt by Parliament to shift the focus from crisis-driven, hard-end-service delivery towards prevention and early detection by the formation of new children's services authorities managed by strategic partnerships that would integrate the planning, commissioning and delivery of services.

The Children Act (2004) also made provision for the appointment of a Children's Commissioner for England. The devolved administration in Wales established a Children's Commissioner in 2001. A Children's Commissioner was appointed in Northern Ireland in June

2003 and Scotland's Parliament appointed their commissioner in February 2004. Their roles are to ensure that the views of children are heard in the national public arena. Children's wishes to participate in decision-making in relation to the English appointment was evident in July 2002, when more than 150 children and young people went to the House of Commons to question the Minister of State for Children about the proposals for the Commissioner for England. The young people were clear in their message. They wanted the Children's Commissioner for England to be an independent champion for their rights, with equal powers to those already commissioned in Scotland, Wales and Northern Ireland. However, constraints on the post in England meant that the commissioner had limited powers to carry out formal inquiries into individual children's cases. More recently reforms have been made to the role of the Commissioner in England through the Children and Families Bill (2013) with substantial developments towards children's rights (CRAE, 2013). The Bill recommends:

"...a rights-based mandate, and repeal provisions which allow the Secretary of State to direct the work of the Commissioner" (CRAE, 2013:11).

Although concerns remain about the independence of the Commissioner, CRAE (2013) welcome the proposals made as moving towards independence. CRAE (2013), remain skeptical when they highlight that the secretary of state will preserve the power to appoint and dismiss to the position of Children's Commissioner. The secretary of state will also retain the power to set the budget for the OCC (CRAE, 2013).

Brooks (2013) suggests that the Coalition Government is committed to delivering on its policies with respect to young people evidenced through the *'Positive for youth: a new approach to cross government policy for young people aged 13-19'* (DfE, 2011). This policy document outlines the range of measures to be implemented across nine government departments (Brooks, 2013; Davies, 2013). This is a timely piece of legislation as Davey (2010) found in ascertaining the impact of children's participation in decision-making. She found little consistency across the organisations in how children's involvement in decision-making was monitored or recorded.

Eighteen months after implementation of *Positive for youth*, the Government produced a document entitled *Positive for Youth – Progress Since December 2011* (HM Government, 2013). In the forward to this report, MPs Edward Timpson (Minister for Children and Families)

and Nick Hurd (Minister for the Civil Society) in commenting on the successes of the initiative suggested:

“.....if we support young people and give them the appropriate tools, they can innovate, they can collaborate and they can have an impact” (p.6).

One of the main features in the *Positive for Youth* initiative is the realisation that all of those engaged with young people should have a vested interest in the future of young people and that young people themselves should have a valid contribution to informing decisions, shaping provision and inspecting quality (HM Government, 2013). Blades et al., (2013) report examples of excellent practice where children have been actively involved in identifying issues and making decisions about how to improve health services alongside adults. However they suggest this is an exception to the rule and more often children are involved in one aspect of the decision-making process which is often tokenistic, as the decisions have already been made by adults or children are not aware of how they have fed into the overall decision being made. Byrne and Lundy (2013) reiterate this and suggest that when policy and other documents are made available in the public domain children are often reliant on adults to make them aware of the existence of the documents and also to ensure that a child-friendly version of the document is made available.

All providers of services are now legally required to involve service users in every stage of their care and children and young people are included in these provisions (Social Care Act, 2008 (Regulated Activities) Regulations 2010, and the Care Quality Commission (Registration) Regulations 2009 cited in RCPCH, 2011). The RCPCH (2011) suggest that regular reviews of policies and practices should be undertaken by all health organisations alongside children to explore where changes and improvements can be made. In addition, these policies should be transparent about how participation activities will contribute to safeguarding and protecting children from harm (RCPCH, 2011).

The public health perspective

Child public health is not simply about providing adult-designed methods for improving child health. Neither is it any longer about screening and surveillance alone. It is, instead, about improving child health and child life chances across whole population groups. At its best, child public health is a social model of medicine incorporating challenges that demand an

understanding of the social, economic and psychosocial culture of childhood. The only way we can do that effectively is to hear the child's perspective. Neither health education nor health promotion initiatives will have the positive outcomes we are searching for if the child's perspective is missing. Children and young people have different experiences from adults about their own health and adults would be advised to avoid making assumptions based on their own experiences alone. In a study carried out by the NCB (Ahmed et al., 2011) to consult young people on the Government Public Health White Paper (*Healthy Lives, Healthy People*) the young participants reported that children and young people need to be involved in planning, designing and implementing public health campaigns. As one young person commented:

"There's a lot of room for the NHS to make things loads better for young people but there's also a lot of room for them to make it quite a bit worse, there's a danger if they don't listen to what we have had to say" (Ahmed et al., 2011: 32).

Children and young people recognize the importance of being healthy but say that they do not always have access to the information and advice that would help them make healthy choices (Morgan, 2010; Children's Society 2012; La Valle et al., 2012). In other research children and young people tell us that they feel public health initiatives are too adult focused, designed by adults and that they fail to address the issues that are important for the younger generation (Brady, 2008; Ahmed et al., 2011). In a study by O'Brien and Moules (2013) the young people who commissioned the research identified mental health as an important public health issue. Other issues that children and young people identified as being important include stress, bullying, depression, home circumstances, and even transport (Cameron, 2007; Brady, 2008; La Valle et al., 2012).

Vulnerable children face more challenges in relation to their health. For example, children in care identify a lack of information available to them about sexual health, alcohol and drugs (CAFCASS, 2008) while children with long-term conditions identified pain management as a key concern (West Bromwich, 2011).

The Children and Young People Health Outcomes Forum (CYPHOF) (2012) emphasises that children are a major target of public health activity because there is time to establish health

routines, behaviours and attitudes to enable them to live healthily for the rest of their lives. The forum goes on to stress the need to include the whole population of children and young people, ensuring that all age groups and all sub-groups with health needs are considered. The report also stresses that:

“This is a once in a lifetime chance to make a step change in the way in which public health considers, reflects and includes the voice and meets the health prevention, promotion and protection needs of its child population. It is imperative this chance is not missed. Their (children and young people) active engagement is an investment for life and a valuable asset to improve the delivery of public services”.

(p.19)

If children’s ‘participation’ is to have substance, it will require those who work with children to seek to ensure children’s perspectives are taken into account as the public health reforms (Health & Social Care Act, 2102) move forward.

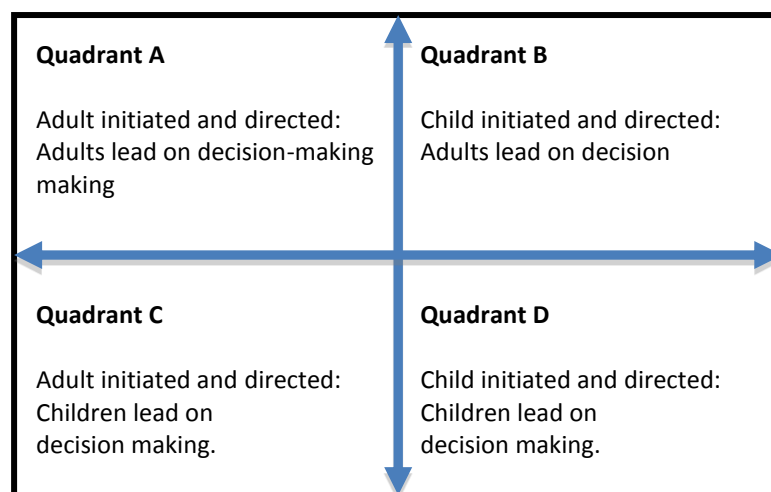
Participation

What do we mean by participation? Participation, for the purpose of this chapter, is about finding ways of incorporating the views of **all** children and young people in decision-making processes within the context of what is possible both institutionally and culturally (Moules, 2005). Participation creates opportunities for children and young people to give their opinions and views and have those views listened to, regardless of how difficult that might be. It is about their opinions being taken seriously in any decision-making process and about them being told exactly how their views have been taken into account. Participation is not an isolated event but is an ongoing process. Children and young people have given their views on what constitutes participation in a number of research studies. Firstly they stress that participation should be respectful with children being treated as persons in their own right, and adults acknowledging that they have something to offer (Neal, 2004). Participation should be genuine, useful and focused on change (Stafford et al., 2003) and finally children and young people need access to the necessary information for them to make informed decisions and they emphasise participation as being about ‘discussions with adults’ (Graham and Fitzgerald, 2010).

Coyne and Gallagher (2011), rather than suggesting participation should be ‘all or nothing’, recommend a continuum of children’s participation. These authors found that although

children wanted to be involved in discussions about their hospital care, their role was often insignificant and the child's parents and health professionals made the main decisions. They found that most of the 7-18 year olds involved in their study wanted to be involved in some aspects of the decision-making process; some children wanted a large role while others wanted to leave the more 'serious' decisions to adults. A wide range of models of children and young people's participation can be found in the literature (Karsten, 2012) including Hart's Ladder of Participation (Hart, 1992) Treseder's degrees of participation (Treseder, 1997) and Shier's pathways to participation (Shier, 2001). One recently developed model is the '*Dual Axis Model of Participation*' (Moules & O'Brien, 2012). The model starts from the position that participation is happening and adds structure to the various ways in which adults and children can co-operate to achieve the aims of an activity. The model proposes four types of participation all of which can be seen to be present to various degrees and at different times in any one activity/project. These four types of participation are shown in Figure 1.

Figure 1. Dual Axis Model of Participation.



Participation then is about taking part in the decision-making process. In practice though, it is a complex and contextual concept and as such has been described as being multidimensional (Moules & O'Brien, 2012) and kaleidoscopic in nature, changing its nature at the "will of the hands in which it is held" (White et al., 1994) from one moment to another. What has been confirmed though is the fact that participation can evolve, starting with participatory intent and building on this within the limits set by participants and the context (Greenwood et al., 1993; Naylor et al., 2002; Moules & O'Brien, 2012).

The current situation

In 2013, there are many examples of good practice in relation to the participation of children and young people in decision-making. For example Davey (2010) reports that since the introduction of the Children Act in 2004:

“...there has been a steady rise in the number of structural mechanisms to enable children to participate in decision-making through student voice and democracy initiatives in schools and youth forums. There has also been a cultural change in the value children, adults and organisations are now placing on children’s views.”
(p.7).

In contrast Davey (2010) suggests the same picture cannot be painted for children’s involvement in decision-making in the health service. Historically children were often denied opportunities to contribute to decisions being made about them or to decisions, which influenced policy change. Davey (2010) points to the national surveys on healthcare and quality of service provision which either usually fail to ask children about their experiences or if these views are sought have little impact on the final decisions made. It seems that there is still a lack of evidence of action and despite a raft of Government policies and guidance, which all stress that every opportunity must be taken to listen to the voices of the young and for their perspectives to be heard, a culture of participation is not commonplace.

In their research paper ‘*We would like to make a change*’, Blades et al. (2013) reviewed local health plans, carried out interviews with local authority health and participation professionals and conducted focus groups with children. This research was carried out to explore children’s participation in strategic health decision-making prior to the implementation of the new reforms to the health service in England from April 2013 (Blades et al., 2013). The detailed findings of this report paint a fragmented picture of children’s participation in local strategic health decision-making; for example only 28% of the 102 local health plans reviewed showed that children had been meaningfully involved in the development, design or evaluation of the plans (Blades et al., 2013). The authors found that there was:

“no coherent national programme of activity to proactively encourage local bodies to include children and young people in strategic health service commissioning or other vital decision-making about NHS provision” (Blades et al., 2013 :2).

Blades et al. suggest that children's participation in local health services has not been fully embedded in everyday practice and there is a reliance on key committed individuals to implement this. Coyne and Gallagher (2011) found that some children reported difficulties in communicating with health professionals and relied on their parents to explain information to them. Cross (2011) reiterates this further and writes that despite changes to policy in the form of children's active engagement to participate in decision-making, vast differences in how practitioners conceptualise participation and equally how they regard participation as relevant in their work is apparent. Limited evidence is available on whether or not children's participation in decision-making improves health and/or social outcomes (Coyne and Gallagher, 2011). Indeed Coyne and Gallagher (2011) acknowledge that for some children participating in decision-making can make situations worse for children in terms of added pressure and responsibility.

In a study exploring the challenges for securing children's rights through policy development in Northern Ireland, Byrne and Lundy (2013) conducted a documentary analysis of policy documents and found that for the most part a child-friendly version of the consultation or the final report was not made available and/or produced. These authors alluded to the fact that consultation with children was often a 'tick-box' exercise. In comparison Davey (2010), in a study commissioned by the OCC to examine children's participation in decision-making in England, found that children were less likely to be involved in setting budgets for services provided for them. Davey (2010) suggests there has been an increase in the number of children involved in the recruitment and selection of staff but there has been little development in the ways in which children are actively involved in decision-making across children's services (Davey, 2010).

Hearing Children's views: the practice

There has never been as much guidance on the practice of involving children and young people in service design and delivery as now. The literature is awash with principles, reports, booklets, handbooks, charters and standards which have been developed at a national level across a range of sectors (for example *Promoting Children and Young People's Participation through the National Healthy School Standard*, Health Development Agency 2004²; *Practice*

² http://www.nice.org.uk/niceMedia/documents/promoting_participation_nhss.pdf

Standards in Children's Participation, Save the Children, 2005³; *Quality Standards for Children and Young People's Participation in CAMHS*, Health and Social Care Advisory Service, 2008⁴; *Not Just a Phase: A Guide to the Participation of Children and Young People in Health Services*, Royal College of Paediatrics and Child Health, 2010⁵; *Hear by Right in Health Services: Children and Young People's participation in PCTs, hospitals and other health settings*, National Youth Agency, 2010⁶). *Hear by Right in Health Services* (Badham and Wade, 2005) is based on the tried and tested standards framework developed by Badham and Wade (2005) for both statutory and voluntary sector organisations to improve their practice and policies on the involvement of children and young people. It is based on the Seven S model of organisational change: shared values, strategy, structures, systems, staff, skills and knowledge and style of leadership. Self-assessment is key to this model and it is developed across 3 levels known as 'emerging', 'established' and 'advanced' with each level built on the last. By using this approach the active involvement of children and young people is embedded in service delivery and is not just an added extra (Badham and Wade, 2005).

Standards have also been developed at a local level, generally only applicable to local agencies. One such example is the Participation Strategy and Charter 2012-2015 *Charter of Participation for Children and Young People in Wirral*⁷ (2006). The Strategy is based on 5 principles, each with a checklist of things to address to enhance children and young people's ability to participate. It includes an evaluation and action plan for organisations to record what they are doing and to plan for future action. However, operationalising standards for children's participation in service delivery will depend on many factors including the type of service, the context, the aim of the process and the children involved. Wright et al. (2006: 6) propose a "whole systems approach" that organisations can take to affect a change or improvement in the way in which they implement participation. They identify four aspects of service development that need to be considered namely the *culture, structures, the practice and review*.

A *culture* of participation needs to be established where there is a shared commitment to the

³http://www.savethechildren.org.uk/sites/default/files/docs/practice_standards_participation_1.pdf

⁴ http://www.hascas.org.uk/pdf_files/HASCASselfassessCAMHSparticipation.pdf

⁵ http://www.rcpch.ac.uk/system/files/protected/page/RCPCH_Not_Just_a_Phase_0.pdf

⁶ [http://www.ayph.org.uk/publications/100_hbr%2022.4.10\[4\].pdf](http://www.ayph.org.uk/publications/100_hbr%2022.4.10[4].pdf)

⁷ <http://www.teenwirral.com/downloads/18>

involvement of children. Senior management support is important and their backing is important for ensuring participation initiatives are agreed and moved forward and for ensuring children's voices are acted on (Oldfield and Fowler, 2004). Indeed a lack of commitment by senior management is still seen as one of the barriers to effective participation (Davey, 2010). Identifying leaders for change, building capacity and effective partnership working are all essential on the pathway to a culture of participation. In developing a culture and to make participation by children meaningful, organisations need to be clear about what they want to achieve and the values that underpin their work. The barriers to participation need to be identified and steps taken to break them down. In particular it may be necessary to promote attitudinal change among adults (Oldfield and Fowler 2004; Cross, 2011). In an organization with a culture of participation, involvement of children and young people is an integral part of the way in which it operates, participation is meaningful and sustainable and is everyone's responsibility (RCPCH, 2010). In a survey by Davey (2010) many professionals and organisations were positive about the involvement of children and young people in participation work and the majority supported the view that there are no decisions in which children cannot be involved. More than two thirds of organisations surveyed stated that they had policies/strategies in place to support participation. However whilst this a positive finding the study also found that participation was limited in some areas notably health services where children's opportunities to be involved in decision making were limited or had little impact. There is some limited evidence of children participating in strategic decisions but again it is patchy (Coad & Shaw, 2008; Burke, 2010; Coyne & Gallagher, 2011).

As the culture changes so too is the importance of developing and planning the *structures* and systems to support it. The structures to be considered include staff, resources and the processes for decision-making and planning. Funding is vital in order to provide the resources needed to implement effective and sustainable participation activities. The need for long-term funding of participation work was top of the list of suggestions by front line workers and organisations for promoting better children's involvement (Davey, 2010). Evidence does point to an increase in resources to support participation (Davey 2010) with increased evidence of training for staff. However, Davey (2010) also reports that there is a lack of training for senior staff and that this needs to be remedied if participation is to be embedded in all parts of an organisation. Participation workers reported that senior staff tend to have a lack of

understanding about the resources required to fully support children's participation (Davey, 2010).

Putting participation into *practice* requires the involvement of all children, regardless of their age, culture and ethnic origin. It means accessing the perceptions of children in hard to reach groups like Traveler children and the children of asylum seekers. It means hearing the voices of disabled children and those with learning difficulties. The environment must be child friendly and one in which they can express their views without fear of feeling intimidated. Different approaches to participation, involving creative and flexible methods, are required and should be appropriate to the context and to the children involved. Importantly children must be given the choice to participate or not, depending on their own personal and contextual situation (Coyne & Gallagher, 2011). Davey (2010) found children in secondary school were more likely to be involved in decision-making than those in primary school with participation by children under the age of 8 years scarce. In childhood research McNamee and Seymour (2012) suggest there is an over-representation of children aged 10-12 years who are either actively involved in the process of research or as data sources. This they argue is potentially down to the competence-based approach where researchers tend to group children in terms of their ages rather than level of understanding. As detailed above, guidance about the 'how' of participation abounds in the literature. One such document is '*Putting Children at the Centre: A practical guide to children's participation*⁸' published by Save the Children (2010). This online resource provides practitioners with clear, easy to use practical guidance regarding the 'how' of participation under the following headings:

⁸http://www.savethechildren.org.uk/sites/default/files/docs/Putting_Children_at_the_Centre_final_%282%29_1.pdf

- advance preparation
 - qualities of a good facilitator
 - tailoring your approach to the evolving capacities of children and young people
 - how children and young people learn
 - creating a child-friendly environment
 - planning a session or activity with children and young people
 - ensuring non-discriminatory practice
 - ensuring the health and safety of children and young people
 - trouble-shooting and dealing with difficult situations
 - involving children and young people in facilitation
- (Save the Children, 2010: 26).

Lastly it is important that a *review* of all the above is carried out in order to make judgments about the effectiveness of the participation process and the impact it has on service design and delivery. Regular review helps to identify the benefits of involvement for the children and for the services they use. Feedback to children enables them to see the impact they have and strengthens the value adults place on children's perceptions (RCPCH, 2012). Even though health services have improved to some degree, the overwhelming evidence points to a lack of monitoring and evaluation in many participatory activities with children (Oldfield and Fowler 2004; Davey, 2010). In the survey by Davey (2010), only 37% of organisations evaluated the impact of participation. In the focus groups conducted by Davey (2010), children who had been involved in the decision-making process criticised adults for not providing them with feedback about how their opinions had influenced the decisions made. They argued that *"having the means to voice an opinion was only the first stage in engaging children in decision-making"* (p.11). Coad and Shaw (2008) in their scoping review of children's choices in health care found that although children want more input into planning and developing appropriate services, there is limited evaluative research on whether these choices are acted upon and whether they inform any positive future changes in service delivery.

The RCPCH (2011) emphasises that children must receive feedback about how their participation has influenced decisions made in service delivery and design. The RCPCH stress that when children see where their participation has made a difference this can be empowering for children. The RCPCH (2011) suggest that children, like adults, are not a homogenous group and different children will want to be engaged in different ways (if at all). Practitioners need to understand the individuality of each child and recognise when it is an

appropriate time to engage them. An example offered by the RCPCH (2011) is that some children might only want to become involved in decision-making, or have ideas for change after they have experienced the service on offer.

A review of the process of participation can be carried out using many of the various models of participation available. Using the Dual-Axis Model (Figure 1) participation can be plotted in the different quadrants during different parts of the activity/event or at the end. The plotting ought to be carried out by both participating children and practitioners and then compared. The result of plotting participation will be to identify how the balance of decision-making, initiation and direction fluctuates during the life of an activity/project. Evaluation of the process can help to improve individual or organisational performance in children's participation and also helps to identify skills or knowledge gaps and develop appropriate training.

CASE STUDIES

The following examples show how children and young people of different ages and abilities can participate at a range of levels in the area of public health from strategic design through to local interventions.

School Nurse Reform – consultations with children and young people.

In 2011 the Department of Health (DH) set up the School Nurse Development Programme and recognized the importance of seeking the views of children and young people in shaping the profession for the future. As a result the development team invited the British Youth Council (BYC), the National Children's Bureau (NCB) and the North West Regional Youth Work Unit (NWRYWU) to seek the views of children and young people. Between them the projects aimed to find out children's and young people's experiences of the existing school nurse system, the priorities for school nursing and more broadly the health service in schools and to ascertain the things that school nurses could do to help children keep healthy. The findings were reassuringly similar across the three projects (Fig.2).

Fig. 2. Findings from three School Nurse Projects.

<p>BYC (2011) <i>Method 1:</i> Online survey Sample: 1599; 11-18 age group.</p> <p><i>Method 2:</i> focus groups at BYC Conventions: Sample: 202.</p> <p>Findings:</p> <ol style="list-style-type: none"> 1. School nurses need to: <ul style="list-style-type: none"> • Be visible and well known • Offer early help • Offer choice 2. Young people want to offer their views about the service they receive. 	<p>NWRYWU (Moxon,2011) <i>Method:</i> Future focused consultation exercise Sample: 50 aged 13-19.</p> <p>Significant findings:</p> <ul style="list-style-type: none"> • Confidentiality – need for a discrete and trusted independent service. • Identified attributes of a ‘good’ school nurse service • School nurse should be known and visible. • Would like access to a range of services in school. 	<p>NCB (2011b) <i>Method:</i> Survey mixture of closed & open questions on 2 pages. Sample: 293 children aged 6-11 in 8 schools across England.</p> <p>Key findings:</p> <ul style="list-style-type: none"> • school nurses need to be visible and introduced to children. • most of those who had seen the school nurse had had positive experience. • school nurses should be kind, caring, friendly, helpful and someone who would listen. • children want help with healthy eating, bullying, problems at home
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Young people were identified as being key partners in the development and their views were said to be “central to the School Nurse Programme of Development” (DH, 2012: 37). The DH states that the key issues raised by the children and young people were accessibility, visibility and confidentiality and that these “*views and ideas were fed directly into the DH’s School Nursing Development Plan*” (DH, 2012: 37). Children and young people and their families are cited as being “advisors to the programme” and “*champions for improving local services and health outcomes*” (DH, 2012: 7) and in a programme co-produced with children, there is a commitment to involving in ongoing service review.

Cyber-bullying – research commissioned by young people.

One of the responsibilities of the National Children’s Bureau is to promote the involvement of children and young people in the work of the Public Health Research Consortium (PHRC). In 2006 the NCB set up The Young People’s Reference Group, which, with further funding from the PHRC and the Wellcome Trust, was able to continue in the form of the PEAR⁹ (Public

⁹ <http://www.ncb.org.uk/pear>

health, Education, Awareness, Research) Project. PEAR consisted of two reference groups, one based in London and the other based in Leeds with a total of 20 young people aged 13-18. As part of their work with the PHRC, PEAR identified mental health and bullying as two of the main public health issues for young people. The young people decided that they would like to commission a research project to explore the impact of cyber-bullying on young people's mental health. They had not found much research on this new form of bullying, and thought that it might still be relatively invisible or inaccessible to adult researchers. The group also felt that, as most of the research on bullying and mental health starts from an adult perspective, they wanted to commission their own research project. As a result they commissioned researchers from Anglia Ruskin University to carry out this project with them (O'Brien & Moules, 2013).

PEAR and the Anglia Ruskin researchers decided on a participatory design using a mixture of quantitative and qualitative methods meaning that the young people were actively involved in all aspects of the research. Prior to the research taking place, PEAR alongside the NCB researchers decided on the topic for investigation, helped write the project specification and short-listed the proposals. PEAR also drafted the questions for possible candidates and contributed to the final commissioning decision. The methods used included an on-line survey using SurveyMonkey aimed at all young people aged 12-18 across England. The survey was followed up with two focus groups. In total 490 young people took part in the study and the key findings are shown in Figure 3. PEAR made a number of recommendations for practice and policy (Figure 4.)

The PEAR project (process and impact) was reviewed following its completion in 2010 (Davey, 2011) using a number of methods including an on-line survey, interviews, focus groups and data collected in formal evaluations during the life of the project. Members of PEAR gave feedback on research proposals being submitted for funding and as one researcher states:

"The PEAR group gave us useful advice and feedback about the proposal, the basic research idea, and also advice about the research design and appropriate methods, ethical issues in working with young people, and involving young people in research"
(Davey, 2011: 20).

In addition public health researchers, who had worked with the PEAR group, said they would be more likely to involve young people in future projects as a result of the PEAR model (Davey,

2011). Impact on the young people was also evident and included a sense of achievement, seeing progress and a feeling of being valued (following input from NICE at one of their conferences) and an advanced understanding of research and evaluation. With regard to the process, the evaluation identified a number of challenges facing practitioners and researchers who want to involve children and young people. These are mainly time constraints, the need for sufficient resources and support for the young people and researchers, and the need for feedback.

Figure 3.

PEAR Project: Cyber-bullying and Mental Health (O'Brien & Moules, 2010).

The key findings:

- Overall twice the number of girls than boys said they had experienced cyber-bullying in some way.
- Of those who said they had been affected by cyber-bullying the most common effect was to their confidence, self-esteem and mental and emotional well-being.
- A quarter of those who had been cyber-bullied (28.8%, n23) stayed away from school and over a third (38.9%, n31) stopped socialising outside school.
- Of those who had been cyber-bullied, over half had sought support mainly from parents and friends.
- Most of the young people thought that cyber-bullying is as harmful as traditional bullying but some feel it does not exist and is down to the victims ability to cope with it.

Fig. 4 Recommendations for practice and policy (O'Brien & Moules, 2010).

Develop educational programmes around awareness for young people, parents/carers and schools.

Deliver education that brings together young people and their families to enhance communication in relation to online media.

Educate young people about what constitutes acceptable behaviour on line.

Support young people to report incidents of cyber-bullying through other young people who could help change attitudes and provide a source of support to young people.

Develop policies that take a holistic approach and which stress the importance of developing values of care and kindness amongst young people.

Sexual Health Services

McCarthy et al. (2012) set out to explore whether using the Internet as a way of educating young people about sexual health would be feasible. The research team carried out 21 focus groups and 6 one-to-one interviews with a total of 67 young people aged 16-22 years. The participants all supported the creation of a web site that had been developed with the input of young people and they felt that existing sites did not address their needs. They identified a range of features that such a web site should have, which included:

- content needs to be straightforward, honest and accurate with the use of uncomplicated words, especially in relation to sexual pleasure, communication, sexually transmitted diseases, pregnancy and emotional issues. Youth speak should not be used;
- look and feel of the website – images should reflect diversity of UK young people, with a clear website name and pages limited in textual content. Content should be updated and new information uploaded every week. Young people wanted social interaction (anonymous) to be possible with videos (real life situations with good actors).

The researchers were able to develop a web site¹⁰, which met the needs of young people and which combines the views of young people with theory-based interactive elements. However McCarthy et al. (2012) highlight the challenges experienced during the project the main one being technical and budgetary constraints within which they had to work. Some of the ideas the young people had, for example the use of discussion boards and regular updating, were impossible to implement for financial and ethical issues. McCarthy et al. conclude that consulting with young people is valuable and allows them to offer key insights to influence interventions for sexual health promotion.

Enabling disabled children's participation

The views of disabled children are no less important than those of other children especially as they are bound to experience significant contact with health services. Though government policy regarding participation by children and young people applies to all children regardless of their ability, participation by disabled children, and in particular by those who rely on technology to communicate, is limited (Franklin & Sloper, 2009). This is more than likely due to a number of practical problems including communication difficulties, time constraints and the need to potentially access disabled children through a range of gatekeepers (Franklin & Sloper, 2009). Traditional methods of data collection are not necessarily appropriate for use with disabled children and young people and so a range of non-traditional methods is

¹⁰ <http://www.sexunzipped.co.uk/home>

becoming available. One example of involving disabled children and young people is the consultation by Turner (2003) who carried out a consultation in Wales to inform the National Children's Framework. One hundred and five disabled children and young people, between the ages of 5-25, were spoken to.

"The sample included children and young people with: autism, cerebral palsy, attention deficit hyperactivity disorder (ADHD), learning disabilities and difficulties, Down's syndrome, mobility and access difficulties, sensory disabilities (primarily speech and hearing impairments), mental health difficulties and chronic illness" (Turner 2003: 4).

The methods used to collect data were developed with guidance from a group of disabled children and young people and included a focus on activities and games, ranking exercises, draw and write (Horstman et al., 2008) and Makaton. Further guidance on appropriate methods to use with disabled children is available on the Internet (Figure. 5).

Figure 5. **Guidance for involving disabled children**

National Children's Bureau. (2008). *How to Involve children and young people with communication impairments in decision-making*. London: NCB.

http://www.participationworks.org.uk/files/webfm/shop_files/howto_Communication.pdf [accessed 20 February 2014].

Making Ourselves Heard – a national project to ensure disabled children's views are heard. Has a wide range of resources.

<http://www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/making-ourselves-heard> [accessed 20 February 2014].

Disability Toolkit – up to date information on resources, policies, research, examples of good practice.

<http://sites.childrengsociety.org.uk/disabilitytoolkit/> [accessed 20 February 2014].

One of the key conclusions was that disabled children and young people want to have an opportunity to give their views both on service design and provision as this quote from one of the children shows:

“Disabled children and young people should be involved in helping to make services better. We should be asked about what we would like to see happen to us. Our views should be taken into consideration” (Turner, 2003: 28).

Asking young children for their views.

Even very young children deserve to have their views listened to and it is up to practitioners to learn how to tune in to what babies and young children are saying. The Young Children’s Voices Network¹¹, under the auspices of the NCB, promotes the participation of babies and children up to 5 years old. Listening is the first step in enabling participation, a listening culture values children’s involvement. YCVN (Blades & Kumari, 2011: 8) defines listening as:

“An active process of receiving (hearing and observing), interpreting and responding to communication - it includes all the senses and emotions and is not limited to the spoken word”.

Much of the published work around the participation of young children (especially those under 5) is in the field of early years education. However health practitioners have much to learn from exploring the different ways used by early years practitioners to gather young children’s views. An interesting example here is from a daycare nursery in Leeds who wanted to find out what the babies and children (aged 3 months to 5 years old) thought about their staff ‘uniform’ of a T-shirt with the nursery’s name on it, referred to below as the ‘BB T-shirt’. To include all the children, the staff devised a ‘listening’ activity, which could be adapted to each age group. They placed various pieces of clothing, fabric and staff T-shirts into a large basket. The children were then helped by familiar carers to explore the contents of the basket. Staff observed the children, took photographs, recorded verbal comments and gave the older children the option of drawing pictures. Figure 6 shows what they found.

Figure 6. Findings from the nursery project.

¹¹ <http://www.ncb.org.uk/areas-of-activity/early-childhood/networks/young-childrens-voices-network>

Babies of 3–16 months loved the different textures, bracelets and beads. They did not explore the BB T-shirts.
Children of 16–24 months explored the basket and chose items they wanted to wear, which did not include the BB T-shirts.
Children of 24–36 months selected and discussed favourite items; they showed no preference for the BB T-shirts.
Children of 36–60 months dressed a member of staff to make her beautiful. The only two items they did not select were the BB T-shirts.

Staff concluded that the children did not like the staff T-shirts but instead preferred colour and texture. They stopped wearing the T-shirts.

This example may seem to be dealing with a small issue. However it indicates that if you use the right methods and listen carefully to young children, even babies, you can learn much that could influence not only small areas of practice but also larger policy issues. Other resources available to help encourage listening to babies and young children are shown in Figure 7.

Figure 7. Guidance for listening to young children.

'Listening as a way of life': A set of eight leaflets on a range of topics, containing details of research, practice and methods that work with young children from birth to eight.
<http://www.ncb.org.uk/areas-of-activity/early-childhood/resources/publications/listening-and-participation> [accessed 21 February 2014].

2010. Let's listen Young children's voices – profiling and planning to enable their participation in children's services. London: NCB
http://www.participationworks.org.uk/files/webfm/files/rooms/early_years/Let'slisten.pdf [accessed 20 February 2014].

Clarke, A. and Moss, P. (2011). Listening to Young Children: The Mosaic approach. London: NCB.

Conclusion

This chapter has provided an overview of the case for participation by children of all ages in service design and delivery. The benefits to children and to the services they use are well documented and the increase in participatory initiatives to hear their voices is evident across

all voluntary and statutory organisations, at both a local and national level. The policy background clearly spells out a commitment to listen to the views of children and young people on behalf of the Government. However the reality is not always as effective as it might be and many barriers still exist which mitigate against children's voices being heard and listened to. These barriers stem mainly from the fact that participation is not embedded into organizations and because there is a vast difference between how practitioners perceive participation. The opportunities to involve children, however, are there for practitioners to take up. Participation by children in service delivery will not happen without planning but it is also important to recognise that participation is a dynamic process that develops over time and needs input from all levels including staff, management, children, parents and external organisations.

Key Points

- Involving children and young people in service design and delivery provides benefits for services, for children and young people, recognises children and young people as citizens.
- The *Positive for Youth* initiative acknowledges that all of those engaged with young people should have a vested interest in the future of young people and that young people themselves should have a valid contribution to informing decisions, shaping provision and inspecting quality.
- Child public health is a social model of medicine incorporating challenges that demand an understanding of the social, economic and psychosocial culture of childhood. The only way we can do that effectively is to hear the child's perspective.
- Participation creates opportunities for children and young people to give their opinions and views and have those views listened to, regardless of how difficult that might be.
- Organisations need to take a 'whole systems approach' when changing or improving the way they enable children and young people to participate. Four aspects of service development need to be considered namely the *culture, structures, the practice* and *review*.

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